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### Freedom: A Work in Progress

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# Freedom: A Work in Progress

Rusi Stanev and Sheila Wildeman<sup>1</sup>

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“I had a lot of dreams, but then I was put in the institution, and then I had only one dream – to be free – and nothing else. All my thoughts were around this.” *Rusi Stanev in conversation with Sheila Wildeman, July 19, 2016.*

“(…) Oh, plenty of hope, an infinite amount of hope -- but not for us.” *Franz Kafka in conversation with Max Brod* (Benjamin, 1968).



<FIGURE 1 (Sketch of Rusi by Slavcho Ivanchev (2015) – photo S. Wildeman, 2017) >

## An Untimely Death

Rusi Stanev, survivor of an intransigent system of guardianship and institutionalisation, victor in a ground breaking disability rights case against Bulgaria at the European Court of Human Rights (ECtHR), my partner in this writing project and (for too short a time) my friend, died on March 9, 2017, before our chapter could be completed. He was 61. Questions have been raised about the appropriateness of the care Rusi received in his final days; at the time of finalising this chapter, a formal inquest into the circumstances of his death had not issued in a decision.<sup>2</sup> But whether or not Rusi Stanev's death is proven to be connected to specific failings on the part of one or more state-backed authorities, it cannot in any straightforward sense be attributed to “natural causes”.

Rather, Rusi Stanev's death, like his life, must be understood against the background of the deeply entrenched injustices – structural, systematic -- dealt him over a lifetime. In short, psychosocial disability functioned over Rusi Stanev's lifetime not as a throughway to respectful and responsive supports but rather as a means of legitimising progressively more intense subjection to a coordinate set of harms – deprivation of liberty, forced medication, legal incapacitation, and with these, consignment to deep poverty and social stigmatisation – making his early death as wholly predictable (Thornicroft, 2011; Westman et al., 2012) as it was unjust.

What was less predictable was Rusi Stanev's rise to fame on the world stage as a human rights hero (Lewis, 2012). Even those who did not know Rusi personally will likely, if they have even passing familiarity with the world of disability rights advocacy, have encountered *Stanev v Bulgaria* (2012). This was the first judgment of the ECtHR to recognise placement in a social care home by a guardian as a deprivation of liberty, and to recognise conditions in a social care home as cruel and inhuman treatment. The judgment affirmed, moreover, the right of those consigned to guardianship and institutional social care to directly access the courts in order to assert their rights.

Few, however, are familiar with the frustrating sequelae of *Stanev v Bulgaria* as these played out in Rusi Stanev's life. The stark reality is that when he died, Rusi was still under guardianship and still in an institution. His situation had in certain key respects improved. But he continued to be denied the right to make the most basic decisions about his life without the co-signature of his guardian(s), and the right to live in the community on equal terms with others. Those who celebrated *Stanev v Bulgaria* and who seek to bring about fundamental social change through human rights must ask: What accounts for this disappointing end to Rusi Stanev's story?

This chapter makes the barest of starts on answering that question. Its primary aim is to celebrate, and mourn, Rusi Kosev Stanev's remarkable life: his rising up despite and against the profound forms of subordination to which he was subjected. It is composed of fragments of Rusi's writing that he produced through the VOICES project, including in the last weeks before his death, and Sheila's responses to those fragments. Its subject -- our subject -- is Rusi Stanev's unfinished project: freedom.

### ***Stanev v Bulgaria* Revisited: Rusi Stanev's Story**

*"We are here to die"*



<FIGURE 2. "Residence, Pastra Institution" (photo c. S. Wildeman, 2017)>

<FIGURE 3. "Part of Residence, Pastra Institution" (photo c. S. Wildeman, 2017) >

*My name is Rusi Stanev and I am from the town of Ruse. In 2000, as my sister wanted to take my house, she put me under guardianship. She wanted to remove me from the house.*

*On 12<sup>th</sup> December 2002, I was sent to Pastra institution. There I met people who were very ill. I asked someone, “Why are we here?” and he stated: “We are here to die.”*

*In 2004, two young women came and they recorded a video of me. I spoke in front of the camera and said that defenders of human rights should be there.*

*Then another woman came and helped me to write a request for the prosecutor to lift the guardianship. She promised to give it to him, as I was imprisoned in Pastra institution. The most terrible place – 106 people were imprisoned there.*

*This is how my road to Strasbourg started.*

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Advocates and academics around the world have told and retold Rusi Stanev’s story: the foundation for *Stanev v Bulgaria* (2012), a leading judgment in international human rights law on the rights of persons under guardianship consigned to institutional living, or social care.<sup>3</sup> Rusi’s account begins with his placement under guardianship – or “partial guardianship,” which in Bulgaria is a status requiring a guardian’s co-consent to give effect to legal transactions. The guardian first appointed on Rusi’s file in 2002 was a municipal official in his home town of Ruse whom he never met, then or since. It was she who decided, six days into her appointment, to send Rusi to the Pastra Institution for Men with Psychiatric Disorders: a remote institution in the Rila mountains some 400 kilometres from his home.

The judgment in *Stanev v Bulgaria* makes note of the illegality, even under prevailing Bulgarian law, of the contract for services through which Rusi’s placement was secured and his disability pension diverted to institutional authorities. That contract was signed by the municipal guardian and the institutional Director, with no consent on Rusi’s part despite the statutory requirement of co-consent. This was enough, according to the Strasbourg Court, to establish an illegal deprivation of liberty and so breach of Article 5 of the ECHR (*Stanev v Bulgaria*, paras. 143 & 150). In time, the role of Rusi’s guardian was transferred to the Director of the institution, whose consent was then required in order for Rusi to enter into contracts (including for residential care or tenancy elsewhere) or to secure legal representation.

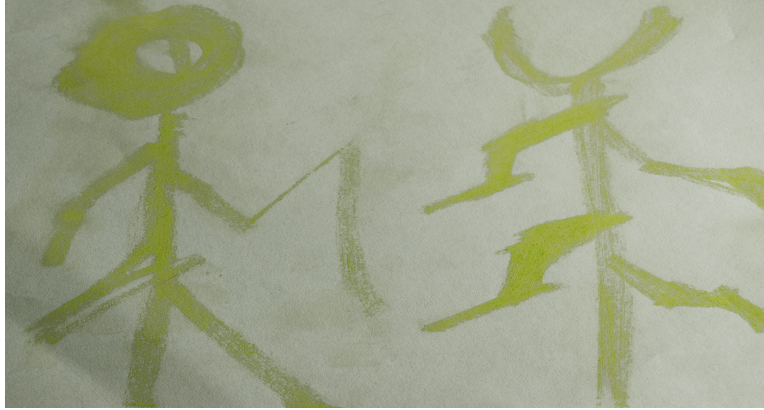
The Strasbourg Court’s judgment further describes (and finds to substantiate a breach of the ECHR’s Article 3) a litany of grim facts about the conditions Rusi endured in Pastra. This is something that Rusi chose not to elaborate on much. Then again, it is difficult to imagine a more effective way of relaying the horror he must have felt upon arriving at this strange and threatening place than his account of the response he was given (by a nameless “someone”) when he sought the reason for their banishment: “We are here to die.”



In his own, concise account, Rusi pares the many painful details of his story to the plot essentials: familial betrayal and institutional abuse, carried out with the complicity of judicial and administrative authorities and those responsible for delivery of social care. It is not often that those so dealt with have the opportunity to tell their side of the story. In November 2016, at a VOICES workshop, we were asked to respond to certain creative writing prompts: “I wish,” “I get so frustrated when,” and things along those lines. Rusi became increasingly agitated and left the room. He said: “How can someone be an ‘I’ when they are not even a person?” That Rusi identified the hero in his story as himself is perhaps the most important result of his involvement in this project. (“I spoke in front of the camera and said that human rights defenders should be there”).

Then again, Rusi was very careful, over many years, to remain the active centre of his life. This was reflected in the extraordinary efforts he made each day to remove himself from the daily drugging, torpor and despair that marked life at Pastra. The Director kept control of his identity papers, so impeding his ability to travel far or make significant transactions (the one time Rusi failed to return from a permitted absence to Ruse, he was apprehended by police and returned to Pastra by institutional staff – a fact that contributed to the Strasburg court’s determination that his placement there constituted a deprivation of liberty). However, he was nonetheless frequently permitted to walk the many kilometres into the village where he “provided domestic help to villagers or carried out tasks at the village restaurant.” Indeed, sometimes Rusi walked a further 10 kilometres to the famous Rila Monastery, where he would pass the time “talking with the foreigners” (as he put it) – accepting their stray coins and cigarettes. The physical stamina and strength of will this took is difficult to imagine, but it explains in part how Rusi Stanev managed to survive Pastra, and, moreover, to keep his memories of what happened there relatively intact while so many others (including those subjected to the daily doses of anti-psychotic medications his early departures enabled him to avoid) could not.

The picture reproduced below (in figure 4) is Rusi’s rendition of the figures he would draw over and over on the road as he travelled from the institution in the woods to the village, the restaurant, the monastery -- and back again to hell. He drew it during a session when Rusi, Aneta Genova (Rusi’s Mental Disability Action Centre (MDAC) lawyer since 2005, and our joint interpreter and supporter during this project) and I enjoyed some down time in Galway. Sometimes I see in this image a symbol of force and violence and domination; other times I see Rusi’s indomitable spirit: his will to bring into being a kind of communion with others, a kind of reciprocity, a dance.



<FIGURE 4: “Sketch by Rusi Stanev” (Photo c. S. Wildeman, 2016)>

### **After Strasbourg**

*I won the case in Strasbourg. The court decreed this home was in reality a prison.*

*I was released from Pastra after the court decision, but nevertheless my guardianship hasn't been lifted and formally persists.*

*So, as I am still under guardianship, I need a lawyer who will be able to lift my guardianship. But I have obstacles in court. It appears that I need a guardian. The court requires a guardian's signature to validate the contract with the lawyer and give her power to act as my attorney. It's only me who can decide who my lawyer will be and who to believe. It isn't fair somebody else gets to decide if I need a defense and who can defend me. I am forbidden only because I am under guardianship.*

*In Bulgaria, they still build defended homes for people with disabilities and under guardianship in depopulated areas. I am in a such place now.*

*I am not an object, they can't move me where they want. I am a human being and I need my freedom and people to communicate with.*



<FIGURE 5. Rusi Stanev in front of the European Court of Human Rights, 2009 (Photo courtesy of Validity Foundation (formerly the Mental Disability Advocacy Centre)). FIGURE 6. “Rusi Stanev and Aneta Genova at restaurant on road between Pastra and Rila Monastery, 2009” (Photo courtesy of Validity Foundation (formerly the Mental Disability Advocacy Centre)).>

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For all its importance in extending human rights oversight to the context of social care, the Strasbourg Court's judgment in *Stanev v Bulgaria* failed to take on Rusi's central arguments (made via Aneta Genova and other MDAC counsel). Those arguments sought to conjoin the principle of least restriction on liberty with positive duties on the state (grounded in Article 8 of the ECHR, and in Articles 12, 14 and 19 of the CRPD) to fashion autonomy-respecting supports for choice and independent living in the community (Flynn, 2016; Nelson, 2012). In effect, the judgment imposed requirements of procedural legitimacy (e.g., access to the courts, and requirements that involuntary social care placements be backed by proper medical documentation) without fundamentally disturbing the premises of disability-based deprivation of liberty and legal capacity in Bulgarian guardianship and social care law.

Rusi's account focuses on the failure of his win in Strasbourg to register in his life in the manner he had believed that it would. The Strasbourg Court ordered Bulgarian authorities to re-examine his social care placement "without delay in the light of the findings of th[e] judgment" (*Stanev v Bulgaria*, 2012, para. 257). Yet in March 2011, prior to the judgment's release, Rusi had already been transferred to a "centre for temporary placement" in Ruse: a facility "located within the grounds of a psychiatric hospital" (Mental Disability Advocacy Centre, 2015). In October 2011, he was transferred to a so-called "family-type" facility again situated inside a psychiatric hospital. Here Rusi's freedom was even more restricted than at Pastra: "[H]e even had to ask for the staff's permission and assistance to go into the yard of the hospital, since the doors were locked." Moreover, "[t]here were no specific programs for reintegration, nor any rehabilitation services provided for him on the basis of his individual needs." While it appears that Rusi signed a contract agreeing to this placement, it is not clear under what circumstances he signed it, nor whether any alternatives were presented (Mental Disability Advocacy Centre, 2015).

Subsequent developments in Rusi's journey through the world of Bulgarian social care reinforce the thinness of the distinction between formal and *de facto* deprivation of the capacity and opportunity to choose (Kukova, 2011). Following expulsion from the "family-type" hospital-based facility (for breaking institutional rules) and a short-lived attempt to live on his own in the community, Rusi moved through a series of social care placements, punctuated by periods of living on the street. Most recently he was placed in another "family-type" facility, now just outside the spa town of Dolna Banya. Here, Rusi reported, the conditions were more comfortable than in other institutions of that type in which he had lived. But he still required permission to come and go, and the facility was a few kilometres from the town -- isolated and hidden away in a manner that he experienced as punishing and stigmatising. Again, his situation was such that he could not interact on equal terms with others, or assume control over his living environment in a fashion others take for granted.

A further layer of frustration following the judgment in *Stanev v Bulgaria* involved Rusi's continued subjection to partial guardianship and the intransigence of Bulgaria's

guardianship regime more generally. In 2017, Bulgaria has still not altered its guardianship law to bring it into compliance either with the ruling in *Stanev v Bulgaria*<sup>4</sup> or with the CRPD (Mental Disability Advocacy Centre, 2016, 2017; Committee of Ministers, 2017). This is despite a law reform process and resultant bill that received the backing of several prominent disability rights organisations and appeared initially to have had significant support from government.

The lack of meaningful change to state laws following *Stanev v Bulgaria* was mirrored in Rusi's life in the Kafkaesque nature of the legal processes through which he attempted to dissolve his partial guardianship. Perhaps the most perplexing element of this part of Rusi's story is the fact that, on repeated occasions and even for years at a time, his formal subjection to guardianship persisted despite the absence of a guardian with authority to act in his case (a turn of events loosely explained by Rusi's periodic shifts in municipal residency and attendant shifts in administrative responsibility for his guardianship). This meant that Rusi was, for extended periods since 2000, without any formal mechanism for obtaining the co-authorisation required to enter into legal transactions, including contracts for social care or residential placements or – critically -- legal representation.

Viewed against this absurdist background, it is perhaps no surprise that Rusi's attempts to challenge his partial guardianship were stymied at every turn. In February of 2012, officials at the Ministry of Justice wrote to the Prosecutor's Office in Ruse requesting commencement of a process to lift Rusi's guardianship. The Prosecutor declined, arguing that neither the Strasbourg Court's judgment nor the Ministry's request constituted a valid basis for commencing such proceedings in Bulgarian law. Following that, with Aneta's assistance, Rusi began the complex and circuitous process of attempting to have the guardianship dissolved. Near the beginning of that process, they learned that Rusi had been without a guardian (although he remained under guardianship) since November of 2012, and so was formally without the power to commence legal proceedings (MDAC, 2015).

Rusi persisted. A new guardian was appointed in May of 2014 -- a member of a supported living association in Pazardzhik Municipality, where Rusi was then residing. Still, a number of preliminary procedural difficulties prevented the hearing of his application for two full years. At least three times, the Regional Courts to which Rusi applied, declined jurisdiction in favour of alternative Regional Courts. There was further wrangling around the appropriate defendant, required payment of court fees, and failure to inform Rusi (or his counsel) of the noted changes in venue. When finally, the Pazardzhik court assumed jurisdiction, it decided of its own motion that it required an independent psychiatric opinion for which Rusi must pay.

These procedural obstacles were accompanied by more substantive ones, primarily the entrenched attitudes of court-appointed experts for whom Rusi's historical psychiatric diagnosis, legal incapacitation and institutionalisation appear to have supported an effectively irrebuttable presumption that he could not manage his own affairs. In May 2016, the Pazardzhik court issued a decision upholding Rusi's guardianship. It stated that what Rusi and his counsel had fundamentally failed to understand was that guardianship

is a protective, not a repressive institution. Imposition of a guardian in Rusi's case was, quite simply, for his own good. The periods during which Rusi had been without a guardian and/or tried to live outside an institution had been marked by instability. He thus required a guardian, reasoned the court, not least to ensure his compliance with institutional rules.

Rusi, with Aneta's help, appealed this decision. Yet the problem was that Rusi was once again (since leaving Pazardzhik) without anyone in the role of his guardian and so was precluded from initiating this legal action. Eventually a new guardian was appointed. Then came another blow: in February 2017, the appellate court denied the appeal. As MDAC's recent submissions to the CRPD Committee relate, Rusi "was in the process of preparing another appeal to the Supreme Court when he passed away. Now, after his death, the case can no longer be continued." (Mental Disability Advocacy Centre, 2017)

Thus, it appears that *Stanev v Bulgaria*, wherein Rusi Stanev established deprivation of liberty and exposure to cruel and inhuman treatment along with illegal obstruction of his right to access the courts, was in the end of little use in protecting him from Bulgaria's coordinate regimes of guardianship and institutionalisation. This should inspire serious and careful reflection on the strategies adopted by human rights advocates to effect individual and systemic change.

### **The Path of Hope (Freedom-in-Reciprocity)**

Two core concepts emerge out of Rusi's late writings. He was no longer writing about his journey out of Pastra or his human rights victory. Rather, he was peeling away those parts of his life to re-engage with his life before guardianship and before – was there ever a time before institutional time? He was engaging, I believe, with fragments of his past in which he saw some hope: some lessons to help reorient and advance the fight against intransigent guardianship and institutionalisation.

I have selected two fragments of Rusi's late writing that speak to two critical elements of that fight -- or rather, critical elements of the reciprocity that is arguably a precondition of freedom. These elements are recognition and resistance. More specifically, the excerpts selected foreground the act of recognising the other through a gift, and of asserting one's difference and one's resistance in the dually creative and destructive form of a prank.

#### *The Gift*

The work that Rusi, Aneta and I did together in preparation for the presentation we gave in Galway in November of 2016 was deep work. It began with gifts. Rusi had been clear about what an appropriate gift would be, and I was grateful for the guidance, as, despite my 49 years, I remain uninitiated in many things, one being the purchase and consumption of cigarettes. I acquired an entire crate of Marlboro Golds at the duty free on my way through Boston – an acquisition that appeared wholly satisfactory when produced in Galway. Rusi in turn gave me a delicate, shiny, red and gold embossed pen stamped with the brand name "piano" which I thought exquisite. He also gave me a couple of postcards showing the resort town of Dolna Banya, the centre of which was a

few kilometres from the social care home in which he was then residing. We would meet there in the summer we said, Aneta, Rusi and me, and explore and write together.

When we parted after that emotional second meeting in Galway (it was emotional at least for me – indeed I surprised Rusi and myself by crying most awkwardly and unbecomingly through our joint presentation), I said I would send Rusi a gift at Christmas time. What he wanted was very clear: more cigarettes. Too late I learned that it was illegal to send tobacco (or alcohol, or firearms) through the post from Canada. In an effort to make up for my blunder – and no longer in time for Christmas, indeed just barely in time for New Year's Day -- I sent an inexpensive watch (in Galway, Rusi had kept pulling at my arm to see my watch), some chocolates, a grand and ornate leather notebook, and somewhere in all that, a few illicit cigars.

What follows is his response to me, which I did not receive until after his death, when the notebook was found among his things. Aneta's friends Milena and Barry translated what he had written inside. I call this initial excerpt "The Gift," and I read it as a meditation on the roots of freedom, or freedom-in-reciprocity.

Rusi Kosev Stanev's notebook

for keeping in touch with Sheila who is from the country of Canada.

I will be writing about my past.

Hello Sheila!!!

*Sheila, right now it is 3pm Bulgarian time and I am sitting down to write you about some of my memories from my past, while in Canada right now it is the middle of the night and you are sleeping.*

*Sheila, first of all I would like to wish you a Happy New Year 2017 and hope that you have much success in your work.*

*I know that you know that I am in an institution and that you empathise with me.*

*Thank you so much for the New Year's present that you sent me. Nobody has ever given me a grand present like that before except for when I was a young student and I received a package from the USSR – a red "pioneer" bandana and a T-shirt and other things that I don't remember as it was a long time ago. Sheila, later on I personally tied the very same red bandana around my sister's neck and shoulders when she graduated from the 2<sup>nd</sup> grade.*

*A memory of mine from my school years is about how the "Radetski" ship was rebuilt in the ship-building factory. Our grade was granted the honour of climbing on board the ship and to sail all the way to the city of Kozlodui and back. I still remember how*



*somebody broke a bottle of champagne on the bow of the “Radetski” ship and then how the ship slid along some rails into the Danube River.*

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Early in our conversations, Rusi was very careful to establish how things stood between us as we entered into this work together. He did this by telling me some stories about work he had done for friends over the years: a man from Ruse with considerable wealth and status whom he had helped make wine; the owner of the café near Pastra where he had gone to do odd jobs in exchange for food and coffee or alcohol, a little money. Rusi and I both understood that what he had of value to share with me were his stories. As he had done many times in his life, he had identified what others valued among the things he had to offer. Indeed, he had a knack for effecting exchanges in conditions resistant to his participation and devaluing of his labour. In this way he was able, throughout his life, to establish relationships of reciprocity, of mutual recognition and respect, across extraordinary imbalances of power.

The idea of the gift – of striking reciprocal relationships across difference through careful consideration of what is valued by the other, by imagining oneself enjoying a gift they would enjoy -- is something Rusi has left me with to think hard about as I and others confront the question of how to disrupt the seemingly intractable logic of guardianship and institutionalised social care. Reciprocal gifting seems to me a device through which we might begin to revisit relationships of charity or control, or for that matter, devalued wage-labour, in a manner that shifts the basic assumptions of contract (use of the other as an instrument of one’s own good) to an alternative imperative involving recognition of the other as a site of innate moral value. This was a shift in orientation about which Rusi was slowly tutoring me in the time I knew him: a lesson to be learned not at the level of theory but at the level of doing, of giving – of micropolitics.

Gifting, as I am positioning it here, stands outside the economy of instrumental exchange and is grounded instead in a felt imperative to fashion creative ways of recognising the other as unique and of value. Yet there are tensions in this idealised way of conceiving relationships of care, support, or co-creation. That is, the economy of gifting seeks to transcend and yet is inevitably shaped by dominant (neoliberal) institutional structures and norms. (Buch, 2014). Indeed, Rusi’s emphasis on gift-giving was informed at least in part by his having been *forced* into a gift economy – his having been consigned to legal incapacity and abject poverty, and so to live on the remains of the wealth generated by others’ valued work and instrumental exchanges.

Ultimately, Rusi’s story of gifting speaks not only to the ways we structure our intimate or private relationships but also to what it means to be gifted by the state. Young Rusi’s excitement on receiving the uniform of the Young Pioneers is shadowed by the knowledge that this gift was at the same time an instrument of control, a demand for conformity. Might a gift from the state (and if so, in what circumstances might it) function not as a tool of control but as a gesture of recognition: an acknowledgement of one’s moral importance? Might a gift from the state (taking the form, say, of a guaranteed

basic income) function to enact reciprocity, both vertically (with authorities) and horizontally (among citizens)? The tender gesture with which Rusi regifted his scarf (fitting it around the neck of the sister who would later send him away) bespeaks the vicissitudes of power and vulnerability that mark our lives: the ways (as Martha Fineman (2010) has observed) we move in and out of positions of power and vulnerability -- a fundamental fact of the human condition that public policy should reflect. At the same time, this tender gesture speaks to the ways we are eased into, and invite others into, allegiance with the institutions that produce our subordination.

All these insights are set into motion, kaleidoscope-like, by Rusi's reflections on the theme of gifts. They arguably bear relevance to the pressing imperative of operationalising the CRPD's Article 12 through the fashioning of regimes of "supported decision-making," and moreover that of integrating Articles 14, 19 and 5 to underwrite a state duty to provide community-based options for residency and care, so as to eradicate or render obsolete rights-denying disability-based deprivation of liberty.

#### *A Prank (School Days)*

*I was sent to a school where I studied for two years through the end of 8<sup>th</sup> grade. [. . .] [I]t was located in a village 30 km from the city – the village was called Tabachka within the district of Ruse, and the school's name was Maksim Gorki. Sheila, I have both good and bad memories from this school. The school was famous for the mischief (of its students) and the following punishments imposed by the Director, Tsvetan. The wire fence around the school was 1 km in diameter. This fence was used as a disciplinary measure in cases of misdemeanour as the entire grade would be made to do laps around the fence if we broke the rules, and then we would go eat breakfast.*

*I have one memory from my chemistry class about how the product "Sodium" would explode when mixed with water. Once, with one of my friends and classmates, Lyubcho, who was stronger than me and who protected me from getting beaten by the other students, we stole a piece of this miraculous sodium from a flask where it was stored in the lab. Then we waited and when there was no one else in the bathroom we placed it into the toilet, watched it swirl around in the water, and then it exploded quite violently. This happened after the end of the day's classes and after the Director, Tsvetan, had already gone home. Every now and then the entire grade had to do laps around the fence in the morning as punishment and sometimes we had to do as many as 5 laps! At the same time, one of us would herd the cows. [. . .]*

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This story of a childhood prank serves as a necessary complement to the earlier passages on gifting. Rusi's time spent at the Maksim Gorki school – a reform school, located 30 km from the nearest village -- of course foreshadows his time in Pastra. It was in this sense the start of a long road of institutionalisation.

Yet Rusi disrupts this apparent foreshadowing and lays a path toward freedom: now through the mechanism of a prank. His story of making the toilets explode with the help

of some sodium and his friend Lyubcho comes off as an ode to creative resistance – to making use of what is at hand to make trouble. I will leave the reader to consider the claim that resistance, like recognition, is necessary to reciprocity. In short, I take this further story from Rusi’s youth as a reminder that our relationships (including relationships of care and support) must make space for difference, for resistance: for the mystery of other minds and others’ rich interior lives.

### **A Work in Progress**



<FIGURE 7. Rusi Stanev’s grave - Dolna Banya, Bulgaria. (c. S. Wildeman, 2017)>

I must conclude this chapter here, though there is so much more I would like to say and to know about Rusi Stanev’s life story, his many stories.

What I will remember most about Rusi Stanev was his fierce will to arrive at a point in his life when he could freely offer others his friendship and his love and be recognised in return for who he was: to be loved back. He walked miles in search of community, and still, at the time of his death, had not arrived. His time bumming cigarettes and coins off foreigners at the monastery in Rila offered those tourist-pilgrims (though they likely did not see it) a profane illumination of the world we have created – one that could consign Rusi Stanev to the special circle of hell that lies at the intersection of legal incapacity and institutionalisation. Rusi made his way up the highway to that sacred place at great cost. His teaching was profound. But it was not understood.

Which brings me back to the question: If a man like Rusi Stanev remained under guardianship and institutionalised to the end of his life, despite a victory at the European Court of Human Rights, what good are human rights?

The answer, I think, must run deeper than accommodating difference so as to enable equal access to the (“free”) market. This chapter, in the spirit of the VOICES project and of the CRPD, suggests that we share responsibility to create the conditions of freedom-in-reciprocity. This sets us (as Rusi has set us) on a path no less daunting than rethinking

the ethical foundations of the social and legal order. The groundwork for such efforts may be discerned in theories that urge a shift from a neoliberal ethos of independence (obscuring the ways that all choices are grounded in supportive conditions and options) to a radical egalitarian ethos of interdependence. Rusi Stanev's stories of forging reciprocity across difference bring these theories to earth – asking us what we are willing to give in order to recognise the deep humanity of the other.

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<sup>1</sup> Rusi Stanev died during the course of the VOICES project. Sheila finished this chapter in memory of him. Rusi's text is in *italics* and is drawn from his presentations to the public workshops for the project and his writing for the chapter before he passed. Sheila's (non-italicised) text reflects on Rusi's writing and draws on her conversations with him since April 2016, when they were paired up through the VOICES project. The support and friendship extended by Aneta Genova to Rusi (over many years) and to Sheila (over the course of this project) made these conversations possible and serves as the foundation for the chapter as a whole. Thanks to the other participants in the VOICES workshops, and to the many people who met with Aneta and Sheila in Bulgaria in July, 2017, including in particular Krassimir Kanev and Slavka Kukova of the Bulgarian Helsinki Committee. Translation of Rusi's writing in Part One was done by Tsvetelina Kanazirska, and in Part Two, by Barry Feno and Milena Mileva-Feno. Special thanks also to Liz Brosnan, Cliona de Bhailis, Maria Laura Serra, Michael Bach and of course, Eilionóir Flynn. And to Amita Dhanda and Gabor Gombos – for modeling the strength of a capacious heart.

<sup>2</sup> Communications with Aneta Genova, July and November 2017. See also MDAC et al. (2017, para. 29).

<sup>3</sup> "Social care home" signifies a publicly funded residential facility for persons lacking other means of accessing long term care and supports (Bulgarian Helsinki Committee, 2002, p.5).

<sup>4</sup> See also *Stankov v. Bulgaria* [2015] ECHR 276.

## Bibliography

Benjamin, W. (1969). Franz Kafka: On the Tenth Anniversary of His Death. *Illuminations* (New York, United States): Schocken Books, p.116.

Buch, E. (2014). Troubling Gifts of Care: Vulnerable Persons and Threatening Exchanges in Chicago's Home Care Industry. *Medical Anthropology Quarterly*, 28(4), pp.599–615.

Bulgarian Helsinki Committee. (2003). *Archipelago of the Forgotten – Social Care Homes for People with Mental Disabilities in Bulgaria*. (Sofia: Bulgarian Helsinki Committee).

Council of Europe, Committee of Ministers. (2017). Notes and decisions on individual and general implementation of *Stanev v Bulgaria* and *Stankov v Bulgaria*. [online] Available at: <http://hudoc.exec.coe.int/eng?i=004-3767> [Accessed 24 Jan. 2018].

Fineman, M.A. (2010). The Vulnerable Subject and the Responsive State. *Emory Law Journal*, 60, pp.251-275.

Flynn, E. (2016). Disability, Deprivation of Liberty and Human Rights Norms: Reconciling European and International Approaches. *International Journal of Mental Health and Capacity Law*, 22, pp.75-101.

Kukova, S. (2011). *Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities: desk report Bulgaria*. (Commissioned by the European Union Agency for Fundamental Rights. Bulgarian Helsinki Committee) [online] Available at: <http://www.humanconsultancy.com/downloads/320-bulgaria-desk-report-fundamental-rights-situation-of-persons-with-mental-health-problems-and-persons-with-intellectual-disabilities> [Accessed 24 Jan. 2018].

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Lewis, O. (2012). Stanev v. Bulgaria: On the Pathway to Freedom. *Human Rights Brief* 19(2), pp.2-7.

Nelson, L. (2012). Stanev v. Bulgaria: The Grand Chamber's Cautionary Approach to Expanding Protection of the Rights of Persons with Psycho-social Disabilities. [online] Available at: <https://www.escri-net.org/node/375437> [Accessed 24 Jan. 2018].

Mental Disability Action Centre. (2015). *Information on the implementation of the European Court of Human Rights judgment of 17/01.2012 in Stanev v Bulgaria, no. 36760/06 by Bulgaria regarding the individual measures ordered by the Court.* DH-DD(2015)454.

Mental Disability Action Centre. (2016). *Communication from NGO (Mental Disability Advocacy Centre (MDAC)) (14/04/2016) on general measures in the cases of Stanev and Stefan Stankov against Bulgaria (Applications No. 36760/06, 25820/08).* DH-DD(2016)515.

Mental Disability Action Centre, Global Initiative on Psychiatry, and Bulgarian Centre for Not-for-Profit Law. (2017). *NGO information to the United Nations Committee on the Rights of Persons with Disabilities For consideration at the 18<sup>th</sup> session when it will adopt a list of issues on the initial report of The Republic of Bulgaria under the Convention on the Rights of Persons with Disabilities.* [online] Available at: [http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/BGR/INT\\_CRPD\\_ICO\\_BGR\\_28482\\_E.docx](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/BGR/INT_CRPD_ICO_BGR_28482_E.docx) [Accessed 24 Jan. 2018].

Thornicroft, G. (2011). Physical health disparities and mental illness: the scandal of premature mortality. *British Journal of Psychiatry*, 199(6), pp.441-2.

Westman, J., Gissler, M., and Wahlbeck, K. (2012). Successful deinstitutionalization of mental health care: increased life expectancy among people with mental disorders in Finland. *European Journal of Public Health*, 22(4), pp.604-6.